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ABSTRACT

The authors consider the possibilities for sociological rehabilitation research in three areas: deviance, minority-dominant relations, and law and politics. Among the areas investigated by medical sociologists are the stigma of disability, discrimination against the physically handicapped as compared to discrimination against minority groups, and the effect of legislation on social change. (SBH)

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APPROACHES TO NEEDED SOCIOLOGICAL RESEARCH ON THE PHYSICALLY HANDICAPPED*

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DEVELOPMENTS IN RESEARCH OPPORTUNITIES ON THE HANDICAPPED

Although Federal support to rehabilitate the disabled has existed for many years, this support was greatly expanded by Public Law 565 in 1954. Research designed to illuminate the process of rehabilitation mushroomed, and by 1965 the Vocational Rehabilitation Administration of the Department of Health, Education and Welfare had supported nearly 1,000 research and demonstration projects (Udane, 1966). In 1965 the VRA and the American Sociological Association co-sponsored a conference at Carmel, California designed to interest more sociologists in doing research on disability, and the results appeared in the 1966 ASA publication entitled Sociology and Rehabilitation (Sussman, 1966). Although the participants gave some attention to the mentally ill and retarded, the emphasis was on the physically handicapped. The valuable fund of suggestions advanced by the ten contributors, all identified in the book as medical sociologists, included cautions about the use of the disease model in research on disability.

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Eight of the ten contributors to a 1976 book entitled The Sociology of Physical Disability and Rehabilitation (Albrecht, 1976a) are also medical sociologists.

The Focus on Rehabilitation

Most of the research on the disabled by medical sociologists has dealt with the process of rehabilitation. Some of it has been essentially evaluation research (e.g., Nagi, 1969). Use has been made of various perspectives on resocialization (Albrecht, 1976b), and on family structure and process (Cogswell, 1976). The sociology of occupations and professions has been used to study the rapid expansion of rehabilitation counseling (Sussman, 1966:Ch. 10), organizational analysis to illuminate the bureaucracy of rehabilitation (Wessen, 1966; Sussman, 1966), and stratification perspectives to relate disability to social class (Alexander, 1976). Still other perspectives are noted later in the paper.

The preoccupation of so much of the research with the process of rehabilitation does not indicate an uncritical use of the medical model. The use of the term "patient" instead of "client" and "trainee" by some medical sociologists (Bloom, 1966) has been criticized by others (Scott, 1966:134-35). Objections have been raised to conducting sociological research within the confines of the separate medical programs provided for people with different physical disabilities (Myers, 1966:37). It has been further noted that chronic disability is stigmatized while temporary illness is not, and the rehabilitator helps the person to learn to cope with it (Scott, 1966:134-38). Rehabilitation requires a

team that is only partly medical. A great many programs of rehabilitation are controlled by physicians, which results in efforts by other team members to achieve rehabilitation despite necessary accommodations to an inappropriate model. Programs outside of hospital settings, such as Goodwill Industries and other sheltered workshops, have been little studied by medical sociologists (Wessen, 1966:164-78).

The Civil Rights Impetus

Employability and economic independence have continued to be dominant considerations in many if not most programs of rehabilitation, perhaps especially for the blind (Scott, 1967, 1969), but by the mid-1960s there was increasing support for helping the disabled to perform better in family and other non-economic roles (Straus, 1966:24-34). The handicapped were not mentioned explicitly in the broad Civil Rights Act of 1964, but basic rights were established for them in the Rehabilitation Act of 1973. The latter act includes provisions that the handicapped cannot be excluded from any program receiving federal financial assistance, or from employment in any business doing work for the government, that buildings must be made accessible to the disabled, and that hospitals and universities must develop special provisions to enable the handicapped to use their facilities effectively. In 1977 HEW ruled that the handicapped must be included in affirmative action programs designed to implement the Equal Pay Act of 1963.

The 1975 Congress passed Public Law 94-142, requiring that handicapped children have full access to free public education, regardless of the degree of handicap. Each child is to have an individually-prepared program of learning, subject to parental approval and to

challenge in a public hearing. The error of demanding too little of the handicapped child is to be avoided as well as the error of demanding too much. These basic rights are to be enforced in all public schools, whether any federal funds are received or not. These provisions, to be effective in the fall of 1978, will bring many handicapped children to school for the first time, and put increasing numbers of them into regular classrooms. The handicapped will thus become much more visible in schools, and in public life generally, than they have been.

These developments have increased the concern over certain matters that sociological researchers on the disabled have tended to treat somewhat incidentally--such as changing and conflicting values and beliefs about the disabled, the views of handicapped persons and their families toward programs designed for them, conflicting interest groups, prejudice and discrimination against the handicapped, and the social control functions of programs of rehabilitation. There are opportunities for research on such questions in a number of overlapping areas of sociological interest, including deviance, minority-dominant relations, and the sociology of law. Some possibilities for research in these three areas will now be considered.

THEORETICAL PERSPECTIVES

The Sociology of Deviance

The labeling perspective on deviance was proposed by Friedson (1966), at the Carmel conference in 1965, as a major approach to research on disability. Some of the other medical sociologists have followed this lead (Scott, 1969; Safilios-Rothschild, 1970), often

making considerable use of Goffman's views on the management of stigma (Goffman, 1963) and on total institutions (Goffman, 1961). Others, while acknowledging the importance of stigma, have considered it to be an inadequate explanation of disability and incompatible with the rehabilitation model. Gove, for example, argues that rehabilitators attempt to maximize participation in normal activities, an outcome facilitated by facing the limiting effects of one's handicap and by identifying with other similarly disabled persons (Gove, 1976; Gove and Howell, 1974). The extent to which both official and unofficial responses to the handicapped contribute to deviant careers rather than to normal functioning remains an important question.

The sick role, as characterized by Parsons (1951:297-321, 428-79), is one in which the person accepts professional help and is not blamed for being temporarily deviant. This has often been contrasted by medical sociologists with the deviant role of the chronically disabled person, who may be able to minimize the stigma but not to eliminate it (Friedson, 1966:80-81; Nagi, 1966:104-105; Kasselbaum and Baumann, 1965; Goffman, 1963:120). Understanding of the management of the stigma of disability might be facilitated by comparing it with efforts by presumably voluntary deviants to avoid or reduce stigma, such as "passing," public repentance, or techniques of neutralization (Goffman, 1971; Trice and Roman, 1970; Sykes and Matza, 1957). Public acceptance may vary with the presumed causes of disability. For instance, perhaps accident victims are perceived as approximating the sick role more than those whose disability is presumed to be congenital and who therefore have never been physically normal.

Some medical sociologists have identified the increased public acceptance of the belief that effective things can be done about disability as a key factor in the dramatic rise of support for programs of rehabilitation (Strauss, 1966:2-3, 22-31)--a belief closely related to beliefs about the causes of disability and about the presumed degree of personal responsibility for it (Friedson, 1966:74-82). Students of deviance have been giving increased attention to the collective definition of deviant categories, and to the social control functions of organizations for processing deviants, including agencies of rehabilitation (Davis, 1972; Davis and Stivers, 1975). This includes emphasis on the belief systems as well as the differential power of various interest groups, and on changing and conflicting beliefs in society as a whole (Davis, 1975).

Minority-Dominant Relations

Medical sociologists have noted the operation of stereotypes of the handicapped, both in the general public (Straus, 1966:4-6) and in agencies of rehabilitation (Scheff, 1966; Scott, 1969:50-70); and have sometimes characterized behavior toward the disabled as discrimination against a minority group. Discrimination has been noted in employment and education, and agents of rehabilitation have been charged with ignoring the ideas and wishes of the disabled (Safilios-Rothschild, 1976:39-43). Physically handicapped people have been expected to play such restricted roles in the community that they have been marginal and obscure, almost invivisble. When handicapped groups become organized, they often protest against the use of stereotypes in agencies that channel them into a limited set of opportunities (Scott, 1969:14-38, 50-89).

It would be interesting and valuable to know how the range of responses of the handicapped to discrimination compares with that of other minorities. The sense of identity of handicapped groups, and the development of subcultures, in-group organizations, and informal social structures have not been subjects of sociological research, nor of comparison with other minorities. Perhaps the blind are the most politically organized group; the National Federation of the Blind maintains an effective office for lobbying in Washington, D.C. The deaf have national newspapers and journals, fraternities and clubs, professional and athletic associations, insurance societies and churches, and they are highly endogamous (Myers, 1966:41-42). Why are other handicapped groups apparently less inclined to develop their own parallel institutions and subcultures, and what are the consequences? How similar is this to the voluntary segregation and retention of group identity by ethnic and racial groups?

When handicapped groups attempt to defend themselves and improve their statuses, what experience do they have with the kinds of educational, economic, political, legal, and protest strategies used by other minority groups? One issue in minority organizations is the nature, extent, and effects of coalition with other groups. The National Federation of the Blind has vigorously opposed coalition with other handicapped groups, believing that the blind fare better under special agencies for them rather than under umbrella organizations for all handicapped groups. It appears, however, that the combining of groups with different handicaps in the 1970s has resulted in more effective protest and political influence. For example, beginning in 1970 in

New York, the Disabled in Action organization got a number of states to pass legislation forbidding discrimination against the handicapped. The far-reaching federal Rehabilitation Act of 1973 was passed after a heavily publicized wheel chair sit-in at the Lincoln Memorial in Washington. In 1974 the American Coalition of Citizens with Disabilities was formed. It influenced the passage of the 1975 Education for All Handicapped Children Act, and later it exerted pressures that resulted in the promulgation by the HEW of firm guidelines for implementation of the act (Kleinfeld, 1977:87-88). Comparison is in order with the civil rights activities of racial, ethnic, and women's organizations and coalitions.

Sociology of Law and Politics

Enough has been suggested above concerning group contests over legislating and enforcing legal norms to suggest the relevance of research on the handicapped to legal and political sociology. Conflicts and accommodations among interest groups that support different beliefs and values, and have different amounts of power, are central in the study of law in society (Quinney, 1969:20-30; Chambliss and Seidman, 1971:63-73; Akers and Hawkins, 1975:5-15). Legal provisions for the handicapped have been portrayed by some medical sociologists as key developments in a vast rehabilitation movement (Safilios-Rothschild, 1976:43-46; Wessen, 1966:152-54; Krause, 1976; Sussman, 1976; Albrecht, 1976c). This movement provides an excellent setting for research on law and social change.

The rehabilitation movement has challenged both the scope and authority of clinical medicine, which has responded by using the concept

of "comprehensive care" to justify its separate programs of rehabilitation for the blind, the deaf, the cerebral palsied, polio victims, the epileptic, and other medical categories of disability. The proliferation of voluntary organizations and foundations to raise funds and provide care for the disabled has followed the disease orientation, as illustrated by such groups as the National Multiple Sclerosis Society, the National Paraplegia Foundation, and the American Diabetes Association. Much of the federal and state health and welfare service for the disabled is organized in terms of medical categories. Most of the research on disability is conducted, financed and coordinated by the National Institutes of Health, and there are separate institutes for blindness, heart disorders, neurological diseases, and other disease categories. The federal Vocational Rehabilitation Administration attempts to coordinate these separate medical bureaucracies, relate them to educational programs and facilitate employment and comprehensive counseling services (Wessen, 1966:164-70).

The many public agencies and private organizations for helping the handicapped develop vested interests, and exert influence on the creation, interpretation, and application of laws concerning disability. The Veterans Administration exerts a great deal of influence on the laws and governmental services for the handicapped, and the Disabled Veterans organization is very active in lobbying, filing lawsuits, and otherwise influencing public policies on disability. The professional associations of rehabilitation specialists--such as physical therapists, occupational therapists, speech and hearing therapists, special educators, and rehabilitation counselors--represent special interests. So also

do the professional associations of physicians, nurses, social workers, and hospital, school, and public health administrators. Add the manufacturers and distributors of medical aids and other special equipment for handicapped groups, and the picture becomes complex enough to provide challenging research for legal and political sociology.

CONCLUSION

One way to pursue research on such questions as those suggested here is for medical sociologists to focus major attention on them in their work. Some of the most fruitful work on the handicapped has been done by medical sociologists for whom such areas as socialization, the family, occupational sociology, or formal organizations are strong interests. The borrowing of concepts from relevant other disciplines and sub-disciplines is often helpful, but much more valuable are the theoretical explanations, hypotheses, and comparative data. The civil rights impetus has provided increased motivation and opportunity for medical sociologists with strong interests in deviance, minority-dominant relations, and law in society to bring them into their research on the handicapped.

A second approach is for medical sociologists to collaborate with colleagues who have major interests in deviance, minorities, or legal and political sociology. Even quick consultation and criticism can yield benefits, but continuing collaboration will bring the theoretical issues and data of these areas to bear more systematically on the study of the handicapped. Finally, sociologists who have not been

involved in medical sociology ought to find disability a rewarding area for research, especially those who have the substantive interests discussed here, but also those others with special interest in social control, bureaucracy, conflict, power or social change.

Bogdan and Biklen (1977) propose the concept of "handicapism" as a means of integrating research in the three areas of interest discussed in this paper. They suggest that "handicapism" is similar to racism and sexism, that persons labeled "handicapped" experience prejudice and discrimination, and that laws and agencies designed to help them require that these persons be designated officially as members of particular disadvantaged groups in order to receive the promised help. This approach allows for analysis of special interest groups, differential power, and movements to change the position of handicapped persons in society.

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